

**National Cancer Institute (NCI)**  
**National Cancer Advisory Board (NCAB)**  
***Ad hoc* Subcommittee on Population Science, Epidemiology, and Disparities**

Gaithersburg Marriott Washingtonian Center  
9751 Washingtonian Boulevard  
Gaithersburg, Maryland

November 28, 2017  
7:30 – 9:00 p.m. EST

SUMMARY

Subcommittee Members

Dr. Electra Paskett, Chair  
Dr. Deborah Winn, Executive Secretary  
Dr. Francis Ali-Osman  
Dr. Deborah Bruner  
Dr. David Christiani  
Dr. Judy Garber  
Dr. Elizabeth Jaffe  
Dr. Beth Karlan  
Dr. Elena Martinez  
Dr. Mack Roach  
Dr. Margaret Spitz

Other Participants

Dr. LeeAnn Bailey (NCI)  
Dr. Robert Croyle (NCI)  
Dr. Brenda Edwards (NCI)  
Dr. Ann Geiger (NCI)  
Dr. Tom Gross (NCI)  
Dr. Paul Jacobsen (NCI)  
Dr. Leah Kaplan (Digital Infuzion, Inc.)  
Dr. Barry Kramer (NCI)  
Dr. James Lacey (NCI)  
Dr. Timothy Ley (NCI)  
Dr. Doug Lowy (NCI)  
Dr. Elena Martinez (University of San Diego, NCI Board of Scientific Advisors)  
Dr. Kenneth Nock (NCI)  
Dr. Vikrant Sahasrabuddhe (NCI)  
Dr. Norman Sharpless (NCI)  
Dr. Sanya Springfield (NCI)  
Dr. Martina Taylor (NCI)  
Dr. Stacey Vantor (NCI)  
Dr. Joy Wyszneaukas (NCI)  
Ms. Alicia Rosov, The Scientific Consulting Group, Rapporteur

### **Introduction of Members and Opening Remarks**

*Dr. Electra Paskett, Director, Division of Cancer Prevention and Control, Department of Internal Medicine, College of Medicine, The Ohio State University*

Dr. Electra Paskett, Subcommittee Chair, welcomed committee members and other participants to the meeting, in particular Dr. Norman Sharpless, new Director of the NCI. The meeting participants introduced themselves.

### **Review of the Subcommittee's Mission and Proposal for Subcommittee Working Group**

*Dr. Electra Paskett*

*Dr. Deborah Winn, Deputy Director, Division of Cancer Control and Population Sciences (DCCPS), NCI*

Dr. Paskett introduced unfinished business from the Subcommittee's previous meeting, including review of the Subcommittee's charge and establishment of a Working Group. Dr. Deborah Winn, Executive Secretary of the Subcommittee, noted that the Subcommittee's focus always should be to emphasize scientific opportunities and challenges, and individual members should avoid real or perceived conflicts of interest.

Dr. Paskett explained that a Working Group will be formed as an entity separate from the Subcommittee to undertake the background work and research of the committee. The Working Group will comprise all or most of the Subcommittee members, but it will not have authority to make decisions. She introduced a draft of the Working Group's mission statement for the members' review. The proposed mission statement was approved with the addition of "and evaluate" to the charge statement:

The NCAB *ad hoc* Subcommittee has identified areas of focus having high potential impact and the Working Group is charged with identifying and evaluating the current status, barriers to progress, new potential strategic approaches to better address the areas of focus, and potential actions to implement and evaluate the new strategic approaches effectively.

The Subcommittee approved this mission statement, and the NCAB will vote to approve it during the next day's meeting. In response to a question, Dr. Winn explained that because the Subcommittee operates under the rules of the Federal Advisory Committee Act, changing its mission statement would require approval of the entire NCAB, the director of NCI, and authorities in the Department of Health and Human Services.

### **Discussion and Selection of Areas of Focus for the Subcommittee**

*Dr. Electra Paskett*

The priorities agreed upon during this meeting will be the areas of focus for the Working Group. Suggestions had been solicited prior to the meeting, and Dr. Paskett presented a list of topics, noting that one of first steps in each area would be to review the current status to identify strengths and weaknesses of current activities. The Subcommittee will present recommendations to the NCAB based on the Working Group's evaluations in each area.

Dr. Margaret Spitz, Professor, Department of Medicine, Dan L. Duncan Comprehensive Cancer Center Baylor College of Medicine, asked for background information on changes to the Cancer Epidemiology Cohort Program Announcement. Dr. Robert Croyle, Director, DCCPS, explained that funding mechanisms have changed over the years. A recent emphasis has been directed to funding new survivor cohorts, but the current plan is to not include survivor cohorts in the PAR that supports infrastructure-specific funding for other cohorts. Instead investigators are encouraged to fund infrastructure for these cohorts in RO1's or PO1's. The immediate challenge presented by this change is how projects in the current portfolio can compete for RO1s, given that reviewers have difficulty reviewing and NCI has difficulty funding large grants that include funding for infrastructure. A longer-term concern is the need

for a strategy to construct a national population-based infrastructure for observational data collection, which leads to the questions of what kind of data will be needed in 10–15 years and what epidemiology will look like in 10–15 years. The ultimate goal would be a broad, integrated resource that is available to the entire cancer community and supports all types of cancer research, because traditional descriptive epidemiology as built on the traditional registry system no longer is serving the needs of the entire cancer research community.

Dr. James Lacey, Director and Professor, Division of Cancer Etiology, Department of Population Sciences, Beckman Research Institute, City of Hope, observed that epidemiology is shifting from a stand-alone study to a fundamental data system approach guiding research. He suggested that this group could identify ways to integrate epidemiology into the different health care environments.

Dr. Judy Garber, Director, Center for Cancer Genetics and Prevention, Dana–Farber Cancer Institute, Professor of Medicine, Harvard Medical School, noted that these changes will affect a great number of stakeholders and that adopting new approaches will require a trade-off of current benefits. Dr. Croyle responded that any changes will take place over a long period of time, citing the shift in how the NCI's tobacco research program evolved from state grants to an overarching program.

Dr. Paskett summarized the discussion into how to manage the existing cohorts and the need to examine the current portfolio of NCI for cancer survivor research alone and as infrastructure. Dr. Lacey added that the field is 15–20 years behind in data science, which affects the value of the research. Dr. Croyle noted that NIH principles of data sharing and accessibility have high standards setting the NIH apart from private entities, because the systems are built for the whole community.

Dr. Paskett directed the Subcommittee's discussion to the subject of strengthening training of the next generation. The effects of changes in training mechanisms are unknown, and the community is waiting for data on success rates. Dr. Barry Kramer, Director, Division of Cancer Prevention, NCI, noted that the emphasis needs to be on more than just the funding mechanisms. The content needs to be examined, and outcomes need to be evaluated beyond where trainees are professionally and what they have achieved in their careers. Training needs to include reproducibility, measurement accuracy, statistical approaches, and the ability to identify when research is ready for a large randomized trial. Dr. Sanya Springfield, Director, Center to Reduce Cancer Health Disparities, NCI, noted that the physician-scientist is an "endangered species," and training and recruitment are essential.

Dr. Paskett noted that some of the other suggested areas of focus were too granular to be suitable for the Working Group to address, and others, such as financial toxicity, could overlap with other larger topics. Dr. Kramer commented that in addition to survivor and etiological cohorts, a third type of cohort is the screening cohort. Dr. Springfield suggested that another area of focus for disparities could be translational cancer health disparities, a nascent field of research.

Dr. Sharpless commented that examining the nature of disparities and addressing disparities was of interest. Dr. Paskett noted that not all populations that suffer disparities receive the same amount of attention in terms of the science and intervention. The portfolio is not as deep in all the disparity populations as it should be, and the science questions cannot be addressed if the cohorts do not exist. For example, only 6 percent of the NCI Cohort Consortium's study participants are Hispanic; Native American and rural populations are similarly underrepresented. It would be very difficult, however, to launch a large cohort of underrepresented populations because the funding is not available. On the other hand, using existing cohorts supported by other NIH Institutes is problematic because the endpoints in cancer research are the last endpoints. The nature of the disease requires etiological cohorts to last longer and be larger.

Dr. Deborah Bruner, Associate Director, Winship Cancer Institute of Emory University, Professor, Department of Radiation Oncology, Emory University School of Medicine, pointed out that given equal

access, the higher-order questions regarding biological differences can be addressed, however, many disparity populations do not have equal access to care and do not receive the same quality of care. In discussion, committee members observed that genetics do play a role in racial disparities, for example for some cancers, but for other cancers it has been proven that there is no difference in outcomes if patients receive same treatment.

A data gap exists because very few studies measure all the factors that affect disease outcomes, such as access to care, tumor characteristics, race, treatment received, and upstream factors. Dr. Sharpless wondered what would have the most impact on disparities in the United States and whether this is a methodology problem or a big data problem. Dr. Bruner suggested that, financial constraints aside, what is needed is an uber-population cohort with harmonized data collection and oversampling of underserved populations. Dr. Paskett added that data are missing on the social determinants of health, such as income, education, race, and risk factors such as tobacco use. Dr. Mack Roach, Professor, Departments of Radiation Oncology and Urology, University of California, San Francisco, Helen Diller Family Comprehensive Cancer Center, observed that cooperative groups have been told over time to collect less data, not more. Dr. Elizabeth Jaffe, Deputy Director, The Sidney Kimmel Comprehensive Cancer Center, The Dana and Albert "Cubby" Broccoli Professor of Oncology, Johns Hopkins University, commented that the studies conducted by cooperative groups already have been designed and asked if adding a question to such a study would be feasible. Dr. Bruner replied that the cooperative groups represent a missed opportunity; the questions this group is discussing may not be relevant to a particular study, but they may be relevant to the bigger, broader vision of cancer research.

Dr. Sharpless summarized the Subcommittee's discussion as coalescing around four focus points: better use of cooperative groups to address disparities; near-term concerns and long-term goals for existing and future cohorts; the science of survivorship; and training. The last two, survivorship and training, would entail portfolio analysis. Dr. Paskett added that the broad area of disparities had included translational cancer disparities, deficiencies in the portfolio, using a multi-level lens to look at both the positives and the negatives, and developing models.

When NCAB approves these areas of focus, Subcommittee members can volunteer for the Working Group and suggest *ad hoc* members with relevant expertise.

#### Adjournment

Dr. Paskett thanked the participants and adjourned the meeting at 9:00 p.m.

/s/ Dr. Electra Paskett

Dr. Electra Paskett  
Chair

11-29-17

Date

/s/ Dr. Deborah Winn

Dr. Deborah Winn  
Executive Secretary

11/29/2017

Date